

BMJ Open What determines duration of palliative care before death for patients with advanced disease? A retrospective cohort study of community and hospital palliative care provision in a large UK city

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ABSTRACT

Objective: For patients with advanced cancer, several randomised controlled trials have shown that access to palliative care at least 6 months before death can improve symptoms, reduce unplanned hospital admissions, minimise aggressive cancer treatments and enable patients to make choices about their end-of-life care, including exercising the choice to die at home. This study determines in a UK population the duration of palliative care before death and explores influencing factors.

Design: This retrospective cohort study analysed referrals to three specialist palliative care services; a hospital-based inpatient palliative care team, and two community-based services (hospices). For each patient referred to any of the above services we identified the date of first referral to that team and calculated the median interval between first referral and death. We also calculated how referral time varied by age, sex, diagnosis and type of palliative care service.

Participants: 4650 patients referred to specialist palliative care services in Leeds UK between April 2012 and March 2014.

Results: Median age of the sample was 75 years. 3903 (84.0%) patients had a diagnosis of cancer. Age, diagnosis and place of referral were significant predictors of duration of palliative care before death. Age was independently associated ($J=2\ 672\ 078$, $z=-392046.14$, $r=0.01$) with duration of palliative care regardless of diagnosis. Patients over 75 years have 29 fewer days of palliative care than patients under 50. Patients with non-cancer diagnoses have 13 fewer days of palliative care than patients with cancer. Additionally, patients referred to hospital palliative care receive 24.5 fewer days palliative care than those referred to community palliative care services.

Conclusions: The current timing of referral to palliative care may limit the benefits to patients in terms of improvements in end-of-life care, particularly for older patients and patients with conditions other than cancer.

Strengths and limitations of this study

- To the best of our knowledge, this is the largest UK cohort study undertaken to explore duration of palliative care in patients with cancer and non-cancer diagnoses.
- The data used in this study are derived from a live clinical system and as such are likely to represent errors or omissions inherent within that system.
- As the data were anonymised, we were unable to identify which patients were referred to community and hospital palliative care. This may mean that for some patients their first contact with palliative care services could have occurred earlier than reported here.

INTRODUCTION

Specialist palliative care services aim to relieve suffering and improve quality of life for people with advanced diseases. For patients with advanced cancer, several randomised controlled trials^{1–5} have shown that early access to palliative care can improve symptoms, reduce unplanned hospital admissions, minimise aggressive cancer treatments and enable patients to make choices about their end-of-life care, including exercising the choice to die at home, which for more than half of patients with cancer is their expressed preference.⁵ The trials from which this evidence is derived were conducted in North America and the studies vary widely in their definition of what constitutes palliative care services and who provides them. Common components were an assessment and several follow-up consultations by specialist palliative care teams over a period of 2–3 months. Where reported, patients were

recruited and received these interventions about 6–14 months before their death.^{1–5} Collectively, these data suggest that a dose of three to four palliative care contacts applied about 6 months before death is associated with better end-of-life care.

The accumulating evidence to support early referral^{1–10} is beginning to influence policy within the USA. Following a randomised phase III trial in patients with small cell lung cancer, which demonstrated the benefit of early palliative care involvement in terms of quality of life and survival in 2010,¹ the American Society of Clinical Oncology issued guidance recommending that palliative care should be considered early in the course of illness for any patient with metastatic cancer or high symptom burden.⁷ Despite this growing evidence base, within routine clinical practice in the UK palliative care clinicians report that many referrals are made in the last weeks or days of life. This study determines in a UK population the duration of palliative care before death and explores influencing factors.

METHODS

Data and patients

We analysed referrals to three specialist palliative care services in Leeds, UK over a 2-year period (April 2012 to March 2014) relating to 4650 deceased patients. One service was a hospital-based inpatient palliative care team serving an acute hospital and tertiary cancer centre, and two were community-based services (hospices) comprising 18 and 32 inpatient beds, each with its own community home care team. For each palliative care service a data manager employed within each organisation provided anonymised data from their electronic medical record system. For each patient referred to any of the above services, we identified the date of first referral to that team (referrals to community (hospice) palliative care (CPC) can be made by any health professional or the patient; referral to hospital palliative care (HPC) is typically by a health professional within the acute hospital in which the HPC team is based). We calculated the median interval between first referral and death. We also calculated how referral time varied by age, sex, diagnosis and type of palliative care service. The data were systematically checked for outliers, inconsistencies, ambiguous diagnoses and missing data (eg, no date of death). The main variables of interest were age at referral (in years), median time from referral to death (in days), referral location (acute hospital or community hospice), diagnostic grouping (cancer, non-cancer) and subcategories of diagnosis for cancer and non-cancer conditions, as outlined in [table 1](#).

Statistical analysis

All referred adults (n=4650) were included in the descriptive analysis. Median times to death were calculated and the variability was summarised using median absolute deviation (MAD). The median deviation is a measure of scale based on the median of the absolute

deviations from the median of the distribution.¹¹ MAD was used as it is a measure of statistical dispersion that is resistant to outliers. Comparisons between median days from date of referral to death were performed using Mann-Whitney U for cancer versus non-cancer and hospital versus hospice referral. Comparisons for age (<50, 50–74 and 75+ years) were performed using the Kruskal-Wallis test, followed by the Jonckheere-Terpstra test.¹² These analyses were performed using SPSS V.22.0. We used median quantile regression to investigate the association between age and sex-standardised median days to death for diagnosis (cancer vs non-cancer) and place of referral (hospital vs hospice). Diagnosis and place of referral were modelled using multivariable quantile regression analyses. This model permits estimation of how the conditional median, or other quantiles (eg, 10th and 90th centile), of a dependent variable *y* changes with an independent variable *x*. Diagnosis and place of referral were then included into this model. The model was generated using the *qreg* command in STATA. Two-tailed *p* values <0.01 were considered significant.

Patient involvement

Two patients with cancer are co-investigators on the research programme of which the study is part and have informed its design and conduct. They are supporting the active dissemination of the study findings to patients and carers through patient and public involvement networks in a format that can be readily understood by patients, carers and health service commissioners.

RESULTS

Sample characteristics

4650 patients were included in the analysis. 2272 women and 2378 men. The median age of the sample was 75 years; 272 patients were under 50 years, 2014 were 50–74 years of age and 2354 were 75 years or over. In total, 3903 patients had a diagnosis of cancer, 747 had conditions other than cancer. The median duration of palliative care for the whole study population was 34 days (MAD=29 days, indicating that half of the study population had a duration of palliative care that deviated from the median by up to 29 days).

Type of palliative care service

In total, 2746 patients were referred to CPC teams and 1904 to a HPC team. When the services were considered separately (community and hospital), we found the length of palliative care was longer for patients referred to CPC; median 46 days (MAD=38 days) compared with 20 days (MAD=17 days) for referrals to HPC (U=1925555.5, *p*<0.01, *r*=−0.22).

Diagnosis and duration of palliative care

The duration of palliative care varied depending on diagnosis. The median duration of palliative care for patients with cancer was 37 days (MAD=31 days).

Table 1 Patient characteristics in relation to referral to community and hospital palliative care

	Community PC n (%)	Hospital PC n (%)	Total n (%)
Total	2746 (59.1)	1904 (40.9)	4650
Sex			
Men	1420 (51.7)	958 (50.3)	2378 (51.1)
Women	1326 (48.3)	946 (49.7)	2272 (48.9)
Diagnosis			
Cancer	2346 (85.5)	1557 (81.8)	3903 (83.9)
Gynaecological	120 (5.1)	145 (9.3)	265 (6.8)
Haematological	105 (4.5)	26 (1.7)	131 (3.4)
Kidney	66 (2.8)	46 (3.0)	112 (2.9)
Colorectal	253 (10.8)	153 (9.8)	406 (10.4)
Upper GI	394 (16.8)	221 (14.2)	615 (15.8)
Lung	659 (28.1)	232 (14.9)	891 (22.8)
Brain	79 (3.4)	34 (2.2)	113 (2.9)
Head and neck	58 (2.5)	65 (4.2)	123 (3.2)
Breast	132 (5.6)	172 (11.0)	304 (7.8)
Bladder	76 (3.2)	54 (3.5)	130 (3.3)
Liver	45 (1.9)	32 (2.1)	77 (2.0)
Prostate	146 (6.2)	106 (6.8)	252 (6.5)
Skin	44 (1.9)	85 (5.5)	129 (3.3)
Unknown origin	130 (5.5)	51 (3.3)	181 (4.6)
Other cancer	39 (1.7)	135 (8.7)	174 (4.5)
Non-cancer	400 (14.6)	347 (18.2)	747 (16.1)
Dementia	52 (13.0)	–	52 (13.0)
Stroke	19 (4.8)	–	19 (4.8)
Degenerative disease	8 (2.0)	–	8 (2.0)
Other neurological	27 (6.8)	–	27 (6.8)
Heart failure	110 (27.5)	–	110 (27.5)
Other lung	96 (24.0)	–	96 (24.0)
Liver failure	16 (4.0)	–	16 (4.0)
Kidney failure	36 (9.0)	–	36 (9.0)
Other non-cancer	36 (9.0)	–	36 (9.0)
Non-classified diagnosis	–	347 (46.5)	347 (46.5)
Age, years			
<50 years	110 (4)	172 (9)	282 (6)
50–74 years	1082 (39.4)	932 (48.9)	2014 (43.3)
75+ years	1554 (56.6)	800 (42)	2354 (50.6)

Patients with conditions other than cancer had significantly shorter duration of palliative care than patients with cancer, overall median 16 days (MAD=14 days) (U=1 110 511, $p<0.01$, $r=-0.15$); longer for CPC (22 days CPC, MAD 19 days) and shorter for HPC (13 days HPC, MAD 11 days).

Within the patient with cancer population, there was variation in duration of palliative care across the different cancer types; patients with breast or prostate cancer had the longest time between referral and death (median days of 43.5 and 48 days, respectively) and patients with haematological or head and neck cancers the shortest (both with a median of 26 days). A Kruskal-Wallis H test showed that there was a statistically significant difference in number of days from referral to death between cancer diagnoses, $\chi^2(14)=58.337$, $p<0.001$ (figure 1). A breakdown of diagnosis categories for the non-cancer population was only available for the referrals to CPC. These are shown in figure 2.

Patients with dementia or patients who had a stroke had the shortest duration of palliative care before death (median 9 and 5 days, respectively), and patients with motor neuron disease had longest (median 83 days).

Age and duration of palliative care

We found a linear relationship between age and duration of palliative care. Patients over 75 years had a median of 29 days (MAD=25 days) palliative care before death, patients between 50 and 74 years, 38 days (MAD=31 days) and those under 50 years had most, 54.5 days (MAD=47 days), ($J=2\ 672\ 078$, $z=-392046.14$, $r=0.01$).

Multivariable quantile regression

Univariate analysis showed age, diagnosis and place of referral as significant predictors of duration of palliative care before death. The multivariable analysis showed that age is independently associated with duration of

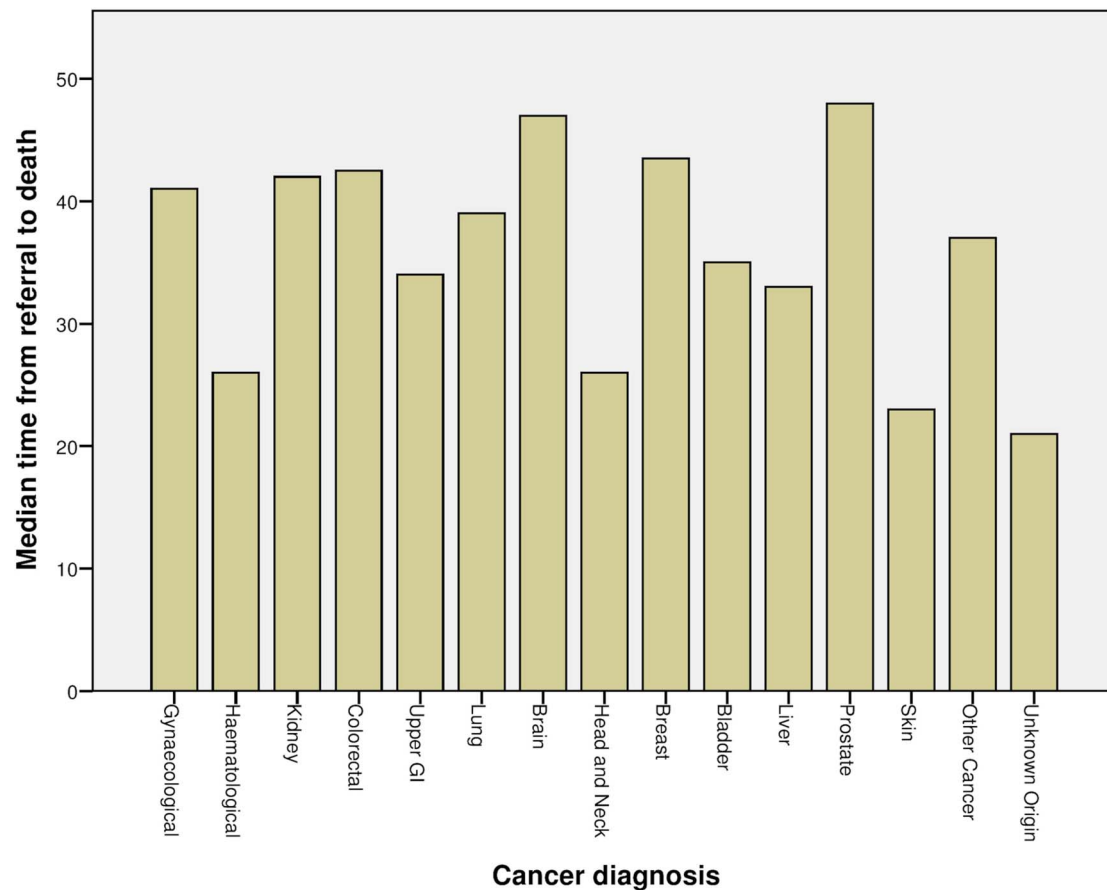


Figure 1 Duration of palliative care in relation to cancer diagnosis.

palliative care regardless of diagnosis, [table 2](#). Patients over 75 years have 29 fewer days of palliative care than patients under 50. Even when controlling for age and sex, patients with non-cancer diagnoses have 13 fewer days of palliative care than patients with cancer. Additionally, patients referred in hospital receive 24.5 fewer days of palliative care than those referred in the community.

DISCUSSION

This is the first population-level study that quantifies duration of palliative care before death, and identifies significantly different durations of palliative care for older patients and those with non-cancer diagnoses.

Comparison with other studies

In terms of studies exploring duration of palliative care globally, our cohort is second only in terms of population size to a US study exploring duration of palliative care in patients with heart failure.¹³ We found the median duration of palliative care in our cohort to be 34 days, significantly shorter than the 6 months the research evidence suggests is optimal.^{1–5} While the duration of palliative care in our cohort appears to be similar to that observed in studies in the USA² and Italy,^{14 15} direct comparison is challenging due to the

differing characteristics of the palliative services and the components of care they provide. It is however possible to broadly categorise the literature into those studies reporting exposure to hospital-based palliative care services and those reporting community or hospice-based services. Studies from the UK,^{16 17} the USA,^{18 19} Korea²⁰ and Singapore²¹ report the median duration of HPC to range from 14.4 to 57 days and studies reporting CPC from Canada,²² Italy¹⁵ and Ireland⁷ report duration to range from 40 to 70 days. These studies provide useful context to the data reported here (20 days to HPC; 46 days CPC) and show the timing of referral to be consistent with that reported in the international literature.

Having a cancer diagnosis is the primary determinant of access to specialist palliative care. During 2012 to 2013, 88% of palliative care inpatients and 75% of new referrals to hospital support and outpatient services in the UK were for people with a cancer diagnosis, even though cancer accounts for only around 29% of deaths.^{23 24} In our study population, 81% had a diagnosis of cancer which is consistent with the existing evidence that patients with cancer are more likely to access palliative care. Extending palliative care to people with non-cancer diagnoses is a key objective of end-of-life care strategies across the UK; however, access to palliative care for patients with non-cancer is hindered by less predictable disease trajectories and greater difficulty in

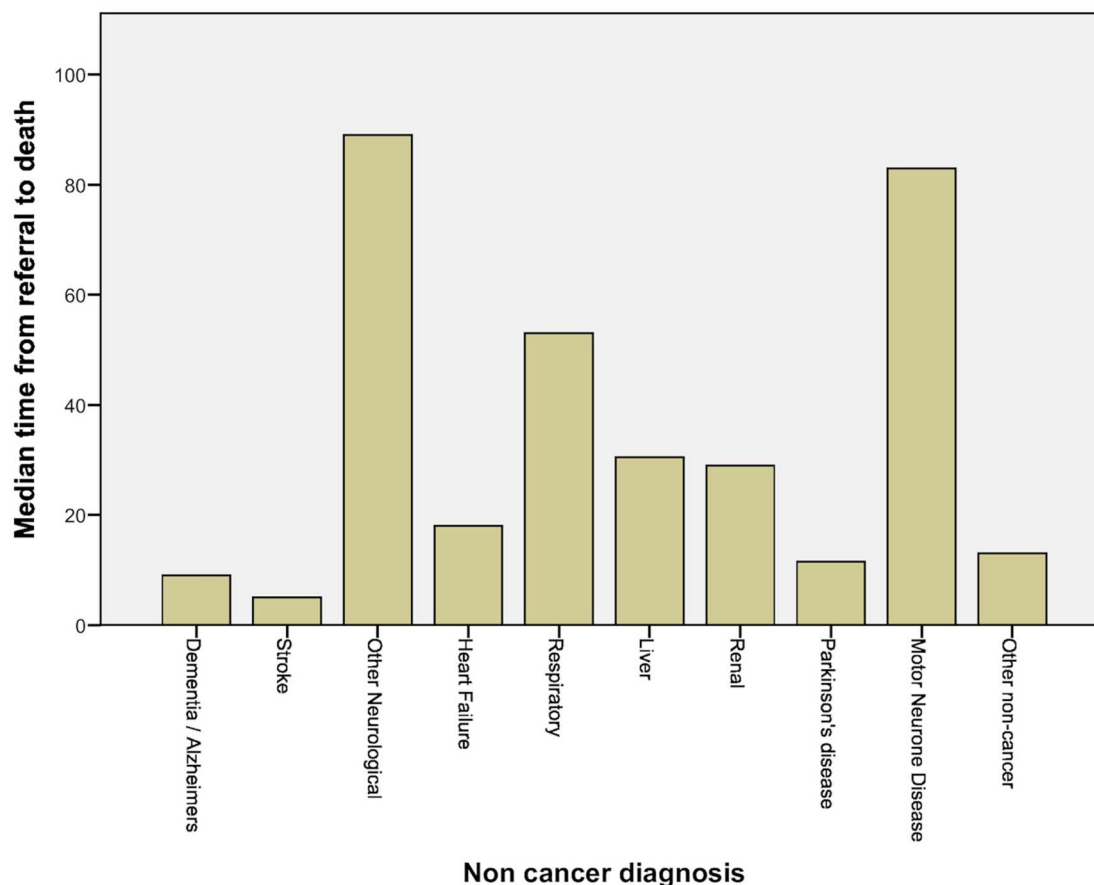


Figure 2 Duration of palliative care in relation to non-cancer diagnosis.

Table 2 Univariable and multivariable model for duration of palliative care

Variable	Univariable model	Multivariable model
Age		
<50 years	–	–
50–74 years	–17 (–27.06, –10.94)+	–20.5 (–29.53, –11.47)+
75 years and older	–26 (–35.13, –16.87)+	–29 (–38.04, –19.96)+
Sex		
Women	–	–
Men	–5 (–8.95, –1.05)	–2.5 (–6.66, 1.66)
Diagnosis		
Cancer	–	–
Non-cancer	–21 (–26.12, –15.88)+	–13.5 (–19.24, –7.76)+
Place of referral		
Hospice	–	–
Hospital	–28 (–32.25, –23.75)+	–24.5 (–28.79, –20.21)+

identifying a terminal stage. Consistent with this, we found that patients with cancer had ~13 days more palliative care than patients with non-cancer. It is already well evidenced^{10 11} that patients with non-cancer are disadvantaged in terms of access to palliative care but it has not been reported previously that the inequity extends to the duration of care.

We found that increasing age is associated with shorter duration of palliative care. The most recent minimum

data set on palliative care activity shows older people are disadvantaged in terms of access; 29% of people accessing specialist palliative care are in the 25–64 age group despite this age group only accounting for 13% of deaths. Whereas people aged 85 or over account for 39% of deaths but represent only 16.4% of referrals to palliative care services.²⁵ Our study is the first to identify and quantify the shorter duration of palliative care in relation to age and so adds to this evidence base. Older

people are therefore disadvantaged in access to, and duration of, palliative care before death.

Limitations

This study has limitations. First, it is based in a single UK city and although our findings are consistent with those reported elsewhere, Leeds is particularly well provisioned in terms of palliative care services and our findings may not therefore be representative of practice in other settings with less robust provision. Second, as de-identified data were used, we were unable to identify situations where a referral to HPC and CPC services had occurred. In Leeds, 17% of patients referred to HPC services receive a subsequent CPC referral; therefore, we expect this extent of overlap to be evident in the data reported here.

Third, as retrospective routinely collected clinical data were used, we do not have data on date of diagnosis, which prevents us from relating the duration of palliative care services to the duration of clinical awareness of disease. Late diagnosis may be a key factor in late referral, though the almost universally short duration of palliative care in our cohort suggests that this factor is unlikely to account for the observed referral pattern.

CONCLUSIONS

This study shows that the current timing of referral to palliative care may limit the benefits to patients in terms of improvements in end-of-life care, particularly for older patients and patients with conditions other than cancer. Research is now urgently needed to better understand how the duration of palliative care reported here impacts on the quality of end-of-life care in order to develop and evaluate service-level interventions.

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Competing interests All authors MIB, LZ, MA, SD have completed the Unified Competing Interest form (http://www.icmje.org/coi_disclosure.pdf available on request from the corresponding author) and declare: no support from any organisation for the submitted work; no financial relationships with any organisations that might have an interest in the submitted work in the previous 3 years, no other relationships or activities that could appear to have influenced the submitted work.

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